

# HOUSE . . . . . No. 2650

By Ms. Fox of Boston, petition of Gloria L. Fox and others relative to the establishment of a lupus erythematosus registry. Public Health.

## The Commonwealth of Massachusetts

### PETITION OF:

Gloria L. Fox	Steven A. Tolman
Dianne Wilkerson	Christine E. Canavan
Shirley Owens-Hicks	

In the Year Two Thousand and Five.

AN ACT TO ESTABLISH A LUPUS ERYTHEMATOSUS REGISTRY.

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

- 1 Chapter 111 of the Massachusetts General Laws is hereby
- 2 amended by inserting after section 25A, as appearing in the 2000
- 3 Official Edition, the following new paragraphs:—
- 4 The department shall, subject to appropriation, establish a Sys-
- 5 temic Lupus Erythematosus (Lupus) registry, by areas and regions
- 6 of the commonwealth, with specific data to be obtained from
- 7 urban, low and median income communities, and minority com-
- 8 munities of the commonwealth.
- 9 The department shall have the authority to require physicians,
- 10 hospitals, laboratories, and other facilities that diagnose such con-
- 11 ditions to report cases of Lupus to the department, and to require
- 12 the submission of such other information pertaining to or in con-
- 13 nection with the reported cases as the department deems necessary
- 14 or appropriate for the purposes of this section.
- 15 To the extent the department deems possible, the registry shall
- 16 be compatible with other national models so as to facilitate the
- 17 coordination of information with other databases.
- 18 The department shall, subject to appropriation, maintain com-
- 19 prehensive records of all reports submitted pursuant to this

20 section. Such reports shall be confidential in accordance with  
21 section 70 and shall be released by the department only upon  
22 written request of the patient, his guardian, executor, attorney, or  
23 other person designated in writing by said patient. Such reports  
24 and records or information contained therein, may also be released  
25 by the department to persons authorized by the commissioner to  
26 conduct research studies or to other persons, but no such studies  
27 shall identify the subjects of said reports or records.

28 Based upon the information provided by the registry, the  
29 department shall provide and disseminate Lupus related informa-  
30 tion which shall included, but not be limited to, geographic pat-  
31 terns or trends in the incidence of each illness in the  
32 commonwealth, screening and testing methods, preventive mea-  
33 sures, and an analysis of the possible effects of environmental fac-  
34 tors. The registry shall provide and disseminate such information  
35 through means including but not limited to establishing a toll-free  
36 telephone information line, providing written materials to hospi-  
37 tals and health care facilities and publishing on the Internet.

38 Nothing in this section shall be construed to compel any indi-  
39 vidual to submit to a medical or departmental examination or  
40 supervision.

41 The department shall promulgate rules and regulations as are  
42 necessary to implement for the administration of this section.